"He looks gorgeous" – iuMR images and the transforming of fetal and parental identities

Abstract (194 words)

The MERIDIAN study examined whether in-utero MRI (iuMRI) improves the accuracy of diagnosis of fetal brain abnormalities, when used as an adjunct to ultrasound anomaly scanning. A diagnostic iuMRI differs from routine ultrasound screening because of its infrequent use and scanning procedure. Nested within this trial, this sociological study explored the acceptability of iuMRI as a technology and its contribution to parental decision making. Our sociological interpretation of the role of iuMR images in prenatal diagnosis draws on narrative interviews with women (and some partners) who underwent MRI imaging at three different centres. Overall, participants found iuMRI helpful in decision-making because it either confirmed or disconfirmed previous results, or provided additional information. Expectant couples experienced the iuMR imaging process as informative, but also as having emotive and practical value. Our paper extends the existing sociological literature on antenatal testing and visualising the fetus, by using iuMR diagnostic imaging to further explore the concept of the unborn entity. Our data suggest that alongside the iuMR images, the 'parental gaze' and accompanying commentary are used by parents to construct and transform fetal and parental identities despite on-going uncertainties about, and shifting social contexts to their pregnancy.

Introduction

Fetal ultrasound imaging has been central to routine screening programmes and detailed anomaly scanning for decades. However, various technical factors and physical limitations can contribute to sub-optimal imaging, leading to erroneous diagnosis and incorrect prognostic information provided to parents (Bijma et al., 2004). The higher frequency of developmental anomalies make diagnostic imaging of the fetal brain particularly challenging (Blondiaux and Garel, 2013). In this scenario, in

utero Magnetic Resonance Imaging (iuMRI)[1] has made a considerable contribution, providing highly reliable and accurate diagnoses because of improvements in spatial and contrast resolution (Griffiths et al., 2012). However the experience of patients undergoing iuMRI compared to ultrasound is markedly different. Ultrasound scans (i.e. at 11-14 and 18-20 weeks gestation) are routine, expected and welcomed. In contrast, iuMRI for brain anomaly is only offered after anomalies are confirmed by specialised ultrasound scanning. Women having iuMRI require more detailed explanation of the procedure which involves entering a large, enclosed and noisy machine. Results are not reported until sometime after the scan, although some clinics do offer parents the opportunity to view the iuMR images afterwards.

The patient experience of iuMRI diagnostic scanning presents a case of idiosyncratic interest (Stake, 2000). Whilst much of the critical debate (Löwy, 2014; Lupton, 2012; Roberts, 2012b) about antenatal imaging has focused on critiquing the ways in which routine ultrasound imaging technologies constitute the problematic medicalization of pregnancy, the use of iuMRI for antenatal screening is not currently (nor likely to become) a routine antenatal event. Women being offered an iuMRI have already been significantly displaced from their previously presumed 'normal' pregnancy narrative. The ultrasound identified brain anomaly is primarily a material-digital entity with a visual status that is made accessible to non-medical specialists. Engaging with the iuMRI process in prenatal diagnosis (PND) for brain anomaly is therefore a qualitatively different experience from engaging with routine antenatal imaging technology.

This paper provides an analysis of women's experiences with this uncertainty, where the materiality of anomaly is made more tangible through a particular form of visual imaging, and what this does in the construction of fetal and parental identities. Mindful of academic debates about the nature of the fetus (Michaels and Morgan, 2016), we sought to be faithful to the perspectives of both mothers and fathers where possible, because of their joint roles as parents.[2]

To contextualise the work, we review the development of MRI and the role of the brain scan in the sociology of neuroscience, linking this back to the sociological literature on fetal ultrasound imaging. We then explore the ideas developed around fetal and maternal identities. Our analysis suggests that, rather than constituting a routine form of medicalization with the potential to disrupt expectations of normality, the first iuMRI for fetal brain anomaly in the PND process represents something more transformational, a resource for parents. As parents work in an uncertain social context, the iuMR image supports them as they construct and reconstruct their unborn entity.

Background

MRI, neuroscience and the medical gaze

Using MRI technology in clinical practice began in the 1980s, as part of a 'broader cultural context of visualisation' (Joyce, 2008: 25; Joyce, 2006; Löwy, 2014) in which visual media have come to dominate Western culture (Sturken and Cartwright, 2001). In medical diagnostics, the senses (sight, touch, hearing) are increasingly dependent on objective mechanical technologies (van Dijck, 2005; Reiser, 1993). On the other hand, the practice of medicine has perhaps been revived, rather than upstaged by new technologies (Latimer, 2013). Research on the initial diagnosis of childhood neurological disabilities (McLaughlin, 2005) demonstrates the importance of parental participation in the diagnostic encounter. However parents to the unborn entity find themselves in a different context, because fetal personhood is not legally established in UK law. Decisions about care pathways following identification of fetal anomaly are, therefore, more heavily influenced by the forms of clinical authority used in interpreting diagnostic imaging or other diagnostic tests [see Caspar (1998:81-86)].

A 'myth of transparency' has grown from the proliferation of diagnostic imaging technologies (van Dijck, 2005; Joyce, 2008). MR images are produced from mapping numerical measurements of nuclear energy absorbed and released in response to magnetic frequencies, a process of 'translation' described as 'painting by numbers' (Joyce, 2008: 24; Joyce, 2006). Radiological analysis of these

images involves cross-referencing with standard body atlases and images taken from different planes and at different times, aiming to diagnose pathology, and therefore requiring isolation of the relevant body part (Prasad, 2005). But integral to the process is the perception, interpretation, and interactive negotiation by social actors, who are influenced by their own social contexts (Burri, 2012; Pickersgill, 2013).

The sociology of neuroscience and mental health (Pickersgill, 2013) is a developing field of study, arising from the brain's association with selfhood and being 'human'. The brain scan and the portability of images, bolsters the authority of neurosciences, even though a complex social matrix exists in the interpretation and use of images. However, while MR imaging expands the scope of the 'medical gaze' in providing a composite radiological vision from multiple digital views of the body, any definitive diagnosis is conditional and limited, and dependent on factors like timing and cost implications (Prasad, 2005). While social science research into neuroscience has focused on the adult brain, far less has been achieved in relation to our area of interest; the fetal brain.

Fetal ultrasound, fetal identity and the MERIDIAN study

Fetal ultrasound imaging progressed from initially being a diagnostic procedure to adoption as a routine screening device (Löwy, 2014), facilitating the construction of the visible fetus as an entity at risk, and therefore requiring observation. The resultant surveillance of the unborn invoked ideas and emotions about fetal and maternal identities (Duden, 1993; Petchesky, 1987; Roberts, 2012a), constructing the fetus as patient and as person. Fetal imaging may transform experiences of pregnancy, potentially marginalising mothers' embodied sensations of their unborn entities (Lupton, 2013). Where the maternal body is perceived as 'receptacle' or edited out of images, fetal dependence on the mother can be overlooked, or even erased (Casper, 1998: 7; Petchesky, 1987). Visual imagery has the potential to represent the fetus as independent of the mother, with its own rights and needs for protection. Consequently, complex moral and ethical dilemmas have arisen about women's relative status and autonomy (Williams, 2006; Williams et al., 2005; Getz and

Kirkengen, 2003), with decisions about pregnancy termination further complicated by non-directive counselling and the priority of women's choice (Williams, 2006; Statham et al., 2006).

Against this backdrop of interest in the social implications of fetal visualisation, we focus on how fetal imaging informs decision making about whether to continue a pregnancy following diagnosis of fetal brain anomaly. Ultrasound images have been depicted as facilitating maternal-fetal bonding, more so now with 3/4D images (Roberts, 2012a). Anti-abortion groups utilise this depiction to argue for the personhood of the fetus, rejecting biomedical forms of representation, and fetal imagery has been used to construct the fetus as empirical reality (Hopkins et al., 2005).

Research on the impact of ultrasound images on women suggests that the 'talk' that accompanies the viewing of the images is important (Mitchell, 2004; Thomas et al., 2017; Hopkins et al., 2005). In iuMR imaging however, the process is different. The woman cannot see the images whilst being scanned, and not all women are able to view the images afterwards. In our study, if parent viewing of iuMR images happened at all, it usually took place directly after the scan. Nevertheless, the way in which the images are viewed and the diagnosis is received is mediated by the interlocutors. Reed et al's ethnographic study (2016b) highlighted how radiologists' communication skills helped women navigate the information provided by the iuMR images. This clinical 'talk' on a sensitive issue has to steer a path between the perceived personification (Mitchell, 2004; Williams, 2005) and objective reality of the fetus (Taylor, 1998; Beynon-Jones, 2015).

Within this sociological critique of visual knowledge, our analysis focuses on how iuMR imaging of the fetal brain is understood by parents, as they construct and reconstruct fetal and maternal (including parental) identities. We consider participants' narratives on their experience of prenatal diagnosis involving iuMRI, exploring whether the radiological gaze makes a difference to women's perceptions of the unborn entity, and how this plays out where a pregnancy is endangered.

Motherhood and the techno-fetus, fetus-baby or unborn assemblage?

The concept of fetal identity has captured the attention of the scholarly world (Boltanski, 2013; Casper, 1998; Casper, 1994; Lupton, 2013; Roberts, 2012a), with implications for maternal status in relation to that of the unborn entity (Williams, 2005). Focusing on the experience of what it means to be pregnant, Lupton (2013: 55) writes about the interconnectedness and inter-embodied nature of pregnancy; while a certain amount of 'loss' is experienced for example, loss of control over one's body and individual identity and a sense of being 'invaded' by a 'parasitic other', there could be gains in the status of being a 'mother' , from the experience of having a 'constant companion' in situ (Lupton, 2013: 59). However the sense that women have of themselves as 'mothers' may be mediated by fetal images, both positively (when it affirms her bodily experience) and negatively (when obstetric images contradict them) (Lupton, 2013: 61).

Casper's (1998) work on fetal surgery vividly captures the fetus as 'patient', with the thesis that the unborn patient is not just technologically determined but a socio-cultural product of advances in Western medicine. The idea of the fetal patient goes hand-in-hand with the development of fetal medicine (Harrison et al., 1990), further fuelling debates about when life begins. Prenatal diagnostic technologies beginning with amniocentesis and chorionic villus sampling (Casper, 1998: 81-82) offered to expectant couples and clinicians new ways of 'seeing' the fetus. Casper claims that expectant couples are often unable to conceive of the fetus as a potential 'baby' until the relevant tests are done to confirm an absence of pathology, therefore the unborn patient is a hybrid subject, or 'technofetus'. And while fetuses are ideal patients because they do not challenge clinicians, fetal patienthood is dependent on maternal patienthood (Casper, 1998: 214). So, the shifts in fetal identity between patient and person are dependent on the conditions and circumstances under which social actors view the fetus. To take into account such shifts in identity between fetus and baby, Blizzard (2007: 49) adopts the conceptual term 'fetus-baby' to capture its dual identity independent of the context. Lupton (2013) argues that the debates about whether the unborn are either relational or as separable from the maternal subject can be reconciled 'by acknowledging the

dynamic nature of the ontology of unborn entities and its shifting meanings according to the context in which they are perceived and experienced.' (2013: 118). She employs the term 'unborn assemblage' to describe the fetus until it is born to reflect this complexity.

The use of MRI in fetal developmental brain abnormalities presents a unique opportunity to explore patient experiences when new technology is introduced into clinical practice across multiple sites in a large clinical study. Our study shows there is more to the 'medical gaze' in this encounter with a new diagnostic modality, as parents construct and reconstruct fetal and parental identities through the 'informative', 'emotive' and 'practical' meanings of iuMRI.

Research context and methods

The MERIDIAN study is a multi-centre prospective observational study of diagnostic accuracy of iuMRI for suspected fetal brain pathology, which recruited women from 16 fetal medicine units (FMUs) across the UK. This paper reports on data from the qualitative sociological study component of M. The sociological study aimed to: 1) Describe, explore and understand how women (and their partners/relatives) experience an iuMRI as part of their fetal diagnosis care pathway, 2) Give an account of perceptions of iuMR imaging on acceptability and decision making and 3) Gain insights into the impact of developments in technology and medical knowledge.

Approval for the study was obtained from an NHS Research Ethics Committee (Ref 11/YH/0006). A fuller account of the recruitment of trial participants to the sociological study is provided elsewhere (Lie et al., 2018). Trial participants completed a questionnaire after they had undergone the iuMRI scan, collecting data on socio-demographic characteristics and 'satisfaction with care' indicators. A second version of the questionnaire was administered 3-6 months following pregnancy outcome, but included a filter question allowing participants to complete an expression of interest (EOI) form for a qualitative interview. Sampling was purposive to achieve diverse representation across the FMUs and MRI centres. We also considered ultrasound diagnosis, whether termination was discussed, the participant's age, pregnancy gestation, and outcome. Of 108 EOI forms received, 41

were selected for interview (at a median 330 days [range 188-430 days] from pregnancy outcome to interview). Twenty one (50%) participants were primiparous (meaning that this was their first baby), eight (19%) had suffered previous pregnancy losses and four (9.5%) had had fertility treatment.

The iuMRI scans were carried out in three MRI centres; one was situated in a Children's Hospital, another in a regional acute tertiary care hospital, while the third was a dedicated academic radiological unit within an acute tertiary care hospital. Altogether 44 interviews were conducted (September 2012 - December 2013). Twenty-five women were interviewed individually, 16 were joint interviews with partners or mothers, while two interviews were conducted with partners on their own. An additional interview was with a partner who requested that his wife (who had been interviewed separately) be present with him. Interviews were conducted in participants' homes and recorded on an encrypted digital voice recorder. Informed, written consent was given by all participants. We utilised a narrative approach to interviewing (Ziebland, 2013), allowing participants to tell their 'story', rather than the interview being dominated by the interviewer. Using a topic guide, participants were prompted to consider key issues, for example, feelings on learning about the anomaly, undergoing the MRI scan, perceived differences between ultrasound and MRI, and decision-making about pregnancy management. The interviews lasted between 1-2 hours. The sound files were stored on a password-secure server. The interviews were transcribed, edited for accuracy, anonymised, and entered into Atlas.ti for indexing and retrieval.

Participants' were assured of interview confidentiality, and their anonymity, promoting openness to voice their opinions freely. The researcher maintained a professional but empathetic stance, enabled by her previous research experience with sensitive issues, and her positionality as a mother and expectant grandmother. A small number of interviewees became tearful in the interview, but wished to continue when the researcher offered to stop. The interviews also explored the support mechanisms in place for each participant, referring them to the national charity Antenatal Results and Choices (ARC, 2017) where necessary.

The interview transcripts (primary documents) were grouped by MRI centre and pregnancy outcome. A generative thematic analysis, adopting an inductive-abductive strategy (Charmaz, 2006), was used to interrogate the data. Because of the analytical focus on participants' experiences, gerunds were employed as codes, and grouped into thematic families. Codes within families were checked for consistency, and compared for similarities and differences across families. Broader themes were then developed from these codes to generate the theoretical framework (Charmaz 1983). To guard against fragmentation of data through the 'code and retrieve' method of data analysis, synopses of each interview were composed. The sociological study team held regular data meetings to verify the coding frame and interpretive analysis, and an interdisciplinary meeting with MERIDIAN team members reviewed the final thematic framework. For this paper, material from the following codes were used: Under the code family 'The value of imaging' we drew upon the following constituent codes: 'viewing the images'; 'getting precision and clarity'; 'having reassurance and hope'; and 'preparing for birth outcome'. For more detailed description, we looked at the code 'explaining the condition through the images' from code family 'Information and communication'. In considering postnatal effects of imaging, we examined the codes 'coping with and managing the outcome'; and 'naming'.

The parental gaze and the utility of the MR image

In exploring the acceptability of the technology, what emerged strongly from the data was the effect that the iuMR images had on the women and their partners and how it was useful to them as they contemplated their pregnancy. Understanding this value to our participants is informed by appreciating the differences in process at the different sites (in terms of patient access to iuMR images), and distinguishing between ventriculomegaly (a developmental condition involving enlargement of the lateral cerebral ventricles), and other brain abnormalities where structures are malformed or missing.

Interviews revealed that participants were told the iuMRI would take hundreds of slides at one sitting and from various angles. At the MRI site in the academic unit, women were able to see this for themselves as they were invited to view a selection of the slides with the radiologist after the iuMRI scan. The radiologist explained his initial findings using the slides, and in some cases would string the slides together to form a video-clip. At the other sites, women were informed about the iuMRI results a week or so after the scan when they met with their fetal medicine consultant, who would be in receipt of a written report of the scan results. At one other site, the expectant couples were given an iuMRI image by the FM consultant.

The expectant couples' reactions to the sight of the fetal brain through iuMRI varied according to the particular brain abnormality that had been identified on the ultrasound scan. In cases with ventriculomegaly, couples focused on the size of the ventricles because the severity and prognosis of the condition was determined by the measurement:

> *the measurements were fifteen point three millimetres….then I had another one a, at [Site A] and their measurement came up about the same and then a couple of weeks later I had an MRI and it showed that there was just over ten millimetres and well that's a big difference, isn't it. – Patricia (N)*[3]

> *…the scan was going to give us a good indication whether erm, you know, things were dropping, rising or the levels were staying the same and so you know I found that just so incredibly stressful. – Jenny (N)*

The reactions of expectant couples who had a diagnosis other than ventriculomegaly were different. Discussions and decisions about ventriculomegaly tend to be focussed on the size of the ventricles and their change during pregnancy. For other conditions, the focus tended to be on understanding the nature and site of the structural abnormality, and the information available on the prognostic implications:

when we were up for the MRI scan, we found out where the hole was in his back. ... it kind of really gave us a heads up, of exactly what was wrong – Tracy (ID)[2]

I think it really hit it home for us because you could literally you know he showed us the pictures of the brain and you could just see this big section missing, you know and he showed us where it should be and what it should look like …. And I think that really helped us to… to understand the kind of… for us the seriousness of, of that whole bit being missing – Cara (TOP)

Away from the multiple social gazes which can imbue the images with rhetorical meaning (Burri, 2008; Joyce, 2008), and in the intimate privacy of the fetal radiological consultation, the images were interpreted as valuable by the expectant couples in three main ways: informative, emotive and practical. The images not only provided crucial visual information but served as a vehicle for emotional expression, and its digital portability enabled sharing and memorialisation.

IuMRI as Informative

A key component of the value of the images for expectant couples lay in the information that they were able to gather from the images in order to confirm or disconfirm the abnormality that was detected by ultrasound. The most common additional brain abnormality found with ventriculomegaly was agenesis of the corpus callosum (ACC).[4] In the following case, the ultrasound raised the possibility of ACC but the structure was identified on the iuMRI:

…so they found the corpus callosum on the, on the MRI which just confirmed that it really hadn't disappeared which was good erm [laughs] – Jessica (N)

Accounts also pointed to how the iuMRI was also helpful in providing new information about the anomaly that was not evident on the ultrasound:

Yeah the shape of the head erm and the nose, [ ] was abnormal too and that was picked up on the MRI which previously wasn't picked up on the other scans that we

had [ ]. So again that er, it helped us that, that way to see exactly… without that we wouldn't be able to you know about that problem - Tom (Partner, TOP)

Participants spoke of the usefulness of the images to the clinicians as they sought to explain the condition with as much clarity as they could to a non-expert patient. This was often a very distressing and confusing time for parents, especially if there were many unanswered questions from the ultrasound scan. For some of them, this additional iuMRI information was crucial in their decision making:

David (N) Yeah he sat us down and explained everything in layman's terms so like you know, you know, this is the, you know this is the brain this is the skull this is the thing, this is the area and look at that, these are the sizes

Sarah Then he showed us the measurements of how he'd

David How he'd measured it and really went into it so we both had a clear understanding of what we were looking at

…the MRI made their job easier to be able to explain things to us – Patricia (N)

it provided me with knowledge that I needed…. I needed to know that the rest of his brain was normal because there is a possibility we would have terminated our pregnancy if we didn't know that – Ella (ID)

Another aspect of the informative value of the images was their usefulness in helping clinicians indicate what couples could expect in terms of the pregnancy outcome, which would help parents to prepare for what was to come:

it sort of then [pause] gave us a chance then to think about you know, whether she'd be delivered on time or whether she'd be delivered early and, certainly from the aspect of the, the erm fluid in her ventricles, er it was then sort of deduced after

seeing them on the MRIs that erm, that she would probably be able to go to the full term – Laura (ID)

he was basically erm confirming what the consultants at [Site F] had said but he kind of gave us more detail of exactly where the hole in the back was and how far down it was erm, and erm … he kind of gave us a bit of information as well of the prognosis and what that would mean and erm – Kelly (ID)

In these participants' accounts of their PND experience, the iuMR images provided a source of reassurance that could be described as qualitatively different from ultrasound images. Depending on how they are spoken about, ultrasound images have been challenged as being a potentially problematic aspect of medical surveillance (see Lupton, 2013), but also for the degree of reassurance they are able to provide to parents (Thomas et al., 2017). It is noteworthy that our participants found iuMRI images to be a helpful addition to their experiences of uncertainty.

IuMRI as Emotive

When asked to describe their reactions at seeing the images, the majority were amazed at the clarity and detail. Those given the opportunity to view a video clip made up of a series of slides were particularly impressed, especially after being given good news:

we thought that maybe there was gonna be some major, major, major problem on it, so I think once we found out that there wasn't, you could relax and actually just enjoy the fact that the pictures you were seeing on the MRI and watching him swallow were so amazing – Jade (N)

Even if the diagnosis following the iuMRI showed an abnormality often associated with a high risk of adverse outcome, expectant couples still took away an element of encouragement from seeing the images of the fetus 'moving'[5]. This encouragement could then contribute to their decision about continuing a pregnancy:

I mean as much as seeing what was wrong with him upset me, you know, when they'd done it, but just seeing him. You could see him moving, you knew he was all right, you know, you could see everything. I just think it were absolutely amazing - Tracy (ID)

Coupled with the reactions of amazement were expressions of relief. Several expectant couples expressed relief when they received news from the iuMRI that the abnormality detected by ultrasound was not as serious as they had originally envisaged, or when they viewed surrounding areas being described as 'normal'[6]:

…then getting the MRI and also being able to see the kind of video. Albeit stills of the baby and the problem and erm you know, the rest of the baby as well, confirmed there were no physical defects other than that physical defect was, and to see it in such clarity, was the kind of a big tipping a big erm aid to our, to my decision making – Nick (Partner, N)

In addition, there was the relief that the development of the brain was seen as 'normal', even if that conceptualisation of normality was limited to the surrounding tissues of the abnormality being further investigated (rather than the entirety of the fetal brain). This was received by parents as a welcome result, in contrast to their earlier experiences in the PND pathway. The earlier anxieties that accompanied the experience of undergoing iuMRI (i.e. uncertainty about whether the fetus was likely to have a disabling abnormality, as well as engaging with a technology that is often seen as physically intimidating) faded into the background, as parents focused on something more positive:

They, when they looked at the MRI yeah, on the MRI they, er the consultant had said that basically he wanted to know erm, if certain bits had been mapped on his head properly, like inside, on the brain and erm [F – everything was there wasn't it] yeah, when I did, when we had the MRI, cos that's what I was worried about cos obviously that can cause severe dis, sort of disability – Cath (N)

For a small minority, they also explained that the images shown to them contributed to their acceptance of the problem, where initially there was disbelief or doubt:

> *Yeah I trusted it more like I said, it's like I believed [ ] I maybe like I said I was in denial by that time I started to believe [ ] ok you know ok there is, you know I know what the doctors saying they're not making it up [ ] ok this is more clear ok– Leila (NSI)*

Emotional turmoil likely impacts parental decision-making, and our findings suggest that iuMR images also impacted expectant couples' state of mind. While for some, the iuMR images represented the ongoing uncertainty of unanswered questions, the majority found benefit from the information resulting from iuMRI. Most of our participants were able to gather reassurances from the increased clarity of the images, both as a result of their interpretations of what they saw and the explanations from the consultant radiologist of the images.

IuMRI as Practical

There was also a practical element in the way that the images were used by expectant couples. A number of them were sent the images by the radiologist as e-mail attachments. This allowed couples to share images with other family members:

> *Yeah, I've got them on, cos I've got emails on my phone so I've actually got some of the pictures on my phone erm and I've erm printed some out…. and I've kept them because who gets to have an MRI scan and get to see their baby inside you like that …– Jill (N)*

One father had an iuMR image of the baby's head when it was three days old and planned to have it as a tattoo and therefore a permanent memento. The iuMR image as a memento was also important for a couple who opted for termination of pregnancy. While they were unwilling to share the photos

of the infant after birth, they were more comfortable sharing the iuMR image of the fetal head with their parents:

> *we had pictures taken when he was when I had him erm and we've kept those but we haven't felt like showing them to anyone erm. [Partner]'s mum's asked, and we just said that we might but, but later you know we actually thought it might upset her more…….they did look at the MRI and they thought that was lovely you know to see the [ ] the full detail and his little face - Cara (TOP)*

With respect to fetal imagery where a pregnancy is terminated, some women who opted for abortion found the ultrasound images of the fetus a helpful part of the termination of pregnancy process (Black, 1992; Kimport et al., 2012). However, there is also the sociologically problematized memorialization of pregnancy loss where fetal images can hold conflicted meanings for parents (Keane, 2009; Black, 1992).

At a practical level, the iuMR image could also be used to help parents to explain the brain anomaly to family and friends:

> *when I've got friends asking questions I'd love to be able to show em oh that's the ventricle that's what they're on about because when I explain it they don't quite get it do you know what I mean but ….whereas pictures speak volumes in my opinion – Mel (ID)*

Thus the utility of the iuMR images was borne out by the informative, emotive and practical aspects of how they could be used by the parents. These meanings of iuMRI arose as a result of our participants' attempts to negotiate the shifting context to their pregnancy, and therefore their changing relational positions to the unborn entity. The 'parental' gaze interacts with the 'medical' gaze, to produce reconstructed meanings of the unborn, held by the parents and clinicians via the iuMR images. In the lived reality of the patient experience, these were the issues that mattered most

to them, and to the clinical community when evaluating the impact of the technology. From a sociological perspective however, the ways they talked about the fetus provided us with the opportunity to interrogate meanings attached to fetal and parental identities.

Fetal and parental identities

Engagement with digital technology has become a more common place, taken for granted feature of modern social life, where embodiment can be understood as a relational assemblage in the context of a digital data knowledge economy (Lupton, 2017). Considering the experiences of those enmeshed in the process of PND diagnosis of a fetal brain anomaly, the introduction of iuMRI offers an interesting counterpoint to much of the existing literature on antenatal imaging. In this part of the thematic analysis, we explore the contribution that fetal iuMR images make to the transformation of identity through the experience of iuMRI in PND for brain anomaly.

The majority of the parents in the study referred to the fetus as 'baby' with only three participants using the term 'fetus'. This is understandable as most parents come to the anomaly scan with all the expectation of seeing a more developed image of their 'baby', and for many, to find out if it would be a boy or a girl. To be told that there could be something seriously wrong with the brain (with all the meanings attached to this part of the body), introduces anxieties and uncertainties that can alter parents' mental image of their baby. The following quotes imply that parents valued the full image of the baby rather than just the isolated brain:

> *Because you get told all these things are wrong you kind of think oh there's no way my child's gonna look normal, he's gonna come out like a donkey really … you know you, you don't know what to expect so you know little things like seeing that video when they put the frames together ….was just so amazing it really made you feel like actually there is a real little baby in there – Ella (ID)*

> *I think it's, the MR puts the baby in place, you know all the pictures that we got sent from [ ] [Site A CI] it's quite, quite easy to make out that's the baby [ ] that's*

[Patient]'s back that's her belly [ ] it, it's in proportion in terms to just have an image of… what could look like a little gremlin. – John (Partner, N)

In the quotes above, the mother felt she benefitted from seeing the video clip, while the father appreciated seeing the baby 'in situ'. They both felt the imaging helped them to prepare for an eventuality that was closer to a normal pregnancy outcome. The idea of the unborn entity being a 'baby' somehow becomes suspended or somewhat qualified with a diagnosis of a fetal anomaly, such that every thread of hope becomes precious. For some parents the iuMR image provided reassurance, not so much of survival but that the fetus would turn out to be sufficiently baby-like to others, and therefore help to re-establish the status of the unborn entity as baby:

…everyone was hanging on to anything that they could see that made her more of a baby – Jessica (N)

This use of the iuMR image to confirm the unborn's identity or personhood status as deserving of the term 'baby' is also evident in other participants' accounts. This mother recounted her reaction to the diagnosis that the baby could have Down syndrome:

Cos I was like kind of looking at the outline of his face and I was thinking he don't look Down syndrome. That's what I was thinking. I don't think I, I said it out loud but I was like thinking he looks beautiful, he looks gorgeous – Michelle (ID)

While one may argue that such an emotional reaction is only that – an emotional reaction and nothing more - it could also be argued that such a gut reaction is evidence or 'an arbiter of reality' (Hopkins et al., 2005: 402), in this case engendering his identity as a beautiful baby. Other parents reacted more positively to Down syndrome, and understandably so in the context of all the other probabilities that they were faced with:

you know it's not the end of the line, there's, there's worse things and we were potentially looking at worse things that could have been wrong with him [mm] so Down syndrome wasn't that bad – Karen (ID)

Some expectant couples referred to the whole experience of viewing the iuMR image as 'surreal', but there was also a sense in which the baby's disability became more 'real'.

he called us back in and he showed us the pictures of the MRI scan and it was actually really surreal being able to watch the baby move you know, and he said he could see her gulping, you know, like, you know, like swallowing, …. because I could see her moving and things it became a little bit more real and, and you know it basically allowed me to make the decision that whatever was going to happen was going to happen and you know, put things in a little bit more perspective – Caroline (N)

Thus one interpretation is that the iuMR image provided this couple with the means through which they could acknowledge the reality of parenting a disabled child, and therefore transform their parental identity on the basis of a more tangible imagined future. But in some cases, this future is tinged with uncertainty because of the limits of technology:

because we don't really know and that's one thing I think that is so difficult, you know, nobody can give us a definite, oh yes, he won't walk, he won't do this and he won't do that. They say he will do these things but they don't know - Nina (ID)

None of the interviews suggested evidence of pressure on parents from a medical discourse in favour of selective abortion on account of an impaired fetus (Sharp and Earle, 2002), bearing in mind that this was in a clinical research context. In contrast to the many ethical issues raised in the literature about termination of pregnancy for fetal anomaly (Crowe et al., 2018), we found our participants had little to say about key issues like pressure in counselling or termination beyond 24

weeks gestation[7]. This is not to suggest that the issues do not exist, but rather, that for the participant group that came forward for our study, these issues were not identified as particularly noteworthy in their accounts of their lived experiences of prenatal diagnosis involving iuMRI.

Another action that was described in the interviews, which established both parental and fetal identity, was the act of naming. This is more apparent in the cases resulting in an infant with a disability or a non-surviving infant. Of these nine cases, eight provided an account of how they decided to name the baby. In one case, the parents felt naming the infant would enable them to be able to talk about him:

> *I think it does help cos I think it helps our families as well because they can, it's not just then that baby you lost it you know or the baby you had to terminate or whatever it's [Baby] isn't it and it's just it's a bit easier I think, think our mums liked it you know they thought it was nice to have you know a name – Cara (TOP)*

In the following case, the naming of the baby depended on what its sex was, which came from the iuMRI scan. In spite of the discovery of the abnormality and probability of a poor outcome, this mother was determined to know:

> *we had the name at around the twenty week scan but we weren't sure what it was a girl or boy, and then when he sort of, once we found out, once we found out he was disabled and we went then from sort of [local town] we went over to the [Hospital 2] and they scanned us before he sent us to [Site M] I said, can I find out what his sex is, what, what the sex is and he said do you want to know and I went… yes cos I always want to know. - Lisa (NSI)*

The desire to find out the sex of the baby, part of the social practice of personifying the fetus (Hopkins et al., 2005; Williams, 2005), confirms the identity of the fetus as 'baby' even though the chances of its survival were in question. This contrasted with another set of parents who regretted

not naming the infant because they then struggled to find a way to refer to him in the company of others:

> *I think, the thing I find probably hardest now is, when I talk about it because it comes up when I, you know when I'm with, I see a group of other mums who I met when I had [Son] and we talk about things and, and if I refer to it, I say 'the baby we lost', but sometimes I think it would be easier if we'd called the baby, I don't know, whatever just to say because then you are calling it a name you know – Kirsty (TOP)*

These parents' accounts suggest that identities are being constructed in the verbal interactions during and after the viewing of the 'images', and even following the loss of the fetus. Boltanski describes this as 'the confirmation through speech of the humanity through flesh of the being in question' (Boltanski, 2013: 48). The naming of the 'baby', we could argue, comes hand in hand with the identity of 'mother', and by association, that of the 'father'. For many parents the identity of the baby becomes more concrete with the viewing of the iuMR image, though it is arguably a visual representation of the fetus that is further away from reality than parents imagine. But at the same time, because parents are able to project social meanings onto the relatively clear images they see, it appears that the iuMR image is able to reinforce the negotiated and constructed status of the memorialised child as a real being (Keane, 2009). The iuMR images might therefore be seen as providing the resources through which parents reconstruct their baby's identity following identification of an abnormality, and therefore refashion their own parent identity in relation to the changing status of the unborn entity. In this way, both the images, and the talk that accompanies them (in the clinic and in the family) constitutes an unusual and interesting case of identity transformation.

Discussion

The emerging body of sociological work on iuMRI has demonstrated the links to core sociological interests. Reed et al (2016b) in particular reference the concepts of uncertainty and diagnosis in their account of lay engagement with iuMRI. In their work on professional perspectives, Reed et al (2016a) draw on Timmermans' 'technology-in-practice' approach to draw out the role of MRI as "a bridging technology, a mediator between different types of professional practice and patient experience" (Reed et al., 2016a: 739). Our findings build on these themes, affirming the role of uncertainty, and strategies for managing uncertainty, as a key feature of the experience for those engaging with iuMRI in the more specific context of PND for brain anomaly. The data from the parents in our study suggest that they were able to utilize their experience of viewing the iuMR images while listening to the radiologists' commentary, to transform their understanding of their baby, reinforcing identities of the parents and the baby, regardless of whether the pregnancy was ended due to the abnormalities identified. Parents were therefore able to repurpose the medical images produced through iuMRI to re-work their connection with their baby (following the disruption created by the identification of an anomaly during screening) and negotiate a transformed, reconstructed parental identity. In this context, patient engagement with iuMRI technology could be considered a potentially rich cultural resource. This does not negate the conceptualization of MRI as part of a technological assemblage that has extended the reach of the medical surveillance of normality. Rather, we suggest that if the social context to iuMRI provision is, at least in part, an enabling one, parents are empowered to use it as a resource with which to assist in the affirmation of their parental identities.

Our research is limited to investigating parents' accounts of their engagement with iuMRI in the context of PND. Understanding parents' perspectives is important, but our interview method is reliant on their retrospective accounts of their experiences. For the future, more in-depth research of the features of the consultations themselves might be productive, to provide a complementary

analysis of the encounters in the clinic – this may be particularly useful should the use of iuMR images become more common place in consultations with parents.

Currently in the UK, iuMRI scans are not widely accessible to pregnant women, whether in the NHS or the private sector, due to the lack of availability of this comparatively expensive equipment, as well as the limited supply of technical expertise required for interpretation. As such, iuMRI scans are much less common an experience, compared to routine ultrasound scans, including more specialised fetal diagnostic ultrasound.[8] An increased capacity for capturing, transforming and sending digital data may increase the accessibility of the images resulting from iuMRI. It is, however, unlikely that iuMRI will become commonplace in the way that fetal ultrasound has become. Whereas fetal ultrasound emerged into the obstetric sphere as a novel way to view a fetus, iuMRI enters the obstetric sphere as an expensive alternative to an already dominant mode of visualisation.

Engaging with the iuMRI process during PND for a fetal brain anomaly is therefore a qualitatively different experience from engaging with routine antenatal imaging technology. Through iuMRI of the brain, pregnant women and their partners attempt to establish more definitively (even if not fully certain) whether the disruption of their expected pregnancy narrative is temporary or something more permanent. The reassurance (Thomas et al., 2017) being sought by parents in these circumstances is therefore a complex mix of reducing (rather than removing) uncertainty in the status of the developing baby, alongside imagining the multiple possible futures for their family, depending on what the images 'say' about their baby. In this instance of deviation from the norm, both the baby and the parents become part of a socio-material assemblage with iuMRI technologies and medical knowledge about fetal development. As such, it provides a fascinating case study with which to explore the way in which both unborn entities and identities are transformed through their engagement with this digital imaging technology. In the context of ongoing debate about digital embodiment (see Lupton, 2017), the engagement with iuMRI and iuMRI findings therefore

represents a fascinating moment in the clinic, transforming parents' understandings of their pregnancy.

While the 'medical' gaze has indeed been expanded by the iuMR imaging (Prasad, (2005), the iuMR image is perhaps more affirming than suggested by writers such as Joyce (2005; 2008).[9] Researchers have commented on the impact that viewing ultrasound images can have on pregnant women who have been given a diagnosis of fetal anomaly (Black, 1992; Van der Zalm and Byrne, 2006; Mitchell, 2004), including some who acknowledge the importance of commentary to images in mediating women's experiences (Mitchell, 2004). Accounts of prenatal ultrasound experience range from those who are sceptical of the medical gaze, suggesting that women are not given enough information (Ahman et al., 2010; Bijma et al., 2008), to those who are more interested in the power of the image to humanise, de-humanise and re-humanise the anomalous fetus during the antenatal journey (Mirlesse and Ville, 2013). The advent of fetal ultrasound imagery fuelled social critiques about the impact that such images can have on constructions of the identity of the fetus.

Feminist concerns about the rights of women and their choice of whether to end their pregnancy have drawn attention to the way these images have been manipulated to convey photographic reality and disempower women. Our findings suggest that access to the iuMR image is viewed positively by women and their partners, as providing useful information to inform decision making about the affected pregnancy, and as having both emotive and practical functions. According to our sociological interpretation, the iuMR image appears to play a pivotal role in what Bolstanski (2013) refers to as the parental project, informing the decisions about abortion that have incalculable dimensions that go beyond the concepts of consumerism and choice. Our analysis demonstrates how parents react to, and interpret, the iuMR images for themselves in tandem with the medicalised explanations of what is visible. These multiple interpretations of the images seem to provide parents

with reassurances about the status of their unborn entity, in particular the likelihood of a surviving baby, and then to estimate likely quality of life following birth. At the same time, iuMR images can be used in establishing parental identities and reinforcing the baby identity of their unborn entity, whether they may be babies with disabilities, an envisaged future child that ended in termination of pregnancy or a baby to be named and memorialised. The power of the image is perhaps most apparent in the cases where parents re-imagined the identity of their affected baby in a positive way, despite the prevailing and dominant discourse about Down syndrome as an unfavourable pregnancy outcome (Choi et al., 2012; Rapp, 2000). Debates about whether personhood is conferred on the fetus following discovery of pregnancy (Lupton, 2012) or following confirmation of absence of pathology (Caspar, 1998), do not quite capture the dynamic nature of fetal personhood during PND. Our findings suggest that the iuMR image can empower women to challenge the medicalised and often negative view of disability, and claim that 'He looks gorgeous' (Michelle). The majority of women who underwent iuMRI conceived of themselves as parents and their unborn entities as their 'babies' regardless of whether they are likely to be disabled, or whether they go through with a termination of pregnancy because of a prognosis of severe impairment[10]. The 'medical' gaze may work to separate the fetal body from its social identity, whereas the 'parental' gaze often does the opposite, reconstructing or reinforcing fetal and parental identities. Academics may attempt to construct the unborn entity as a 'technofetus' or a 'fetus-baby' or the 'unborn assemblage', but it could be argued that this may serve to take us further away from parental epistemologies in the real world.

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[1] We use the term intra uterine MRI (iuMR imaging or iuMRI) to indicate that our research focuses on the experiences of women undergoing MR imaging of a live fetus in-utero. This term is used in preference to fetal MRI, which is a broader term encompassing other forms of MR imaging, such as imaging the fetus post mortem. Where we have used 'MRI', it refers to the technology in general terms.

[2] This contrasts with other situations (Locock and Alexander J, 2006; Atkin et al., 2015) where men's role as a parent may be disregarded or estranged, as their joint role is especially heightened in the context of diagnostic imaging for a fetal brain abnormality.

[3] Normal infant (N), Infant with a disability (ID), Non-surviving infant (NSI), Termination of pregnancy (TOP), according to trial outcome results. All the names used here are pseudonyms.

[4] The corpus callosum is the largest fibre tract in the central nervous system that connects the left and right cerebral hemispheres of the brain.

[5] MRI images are static but strung together to give the impression that they are moving.

[6] Ideas about 'normality' here are taken at face value in bio-medical terms, but as Thomas (2007:15) notes, medical sociology in general is underpinned by a 'social deviance paradigm', in contrast to the social oppression paradigm she associates with disability studies. Fortunately, in several cases, the abnormality resolved during the course of the pregnancy, with normal (N) outcomes.

[7] Only one patient interviewed had strong views about the issue of late termination.

[8] Whilst this takes place in tertiary level hospital units for those with a potential anomaly to be explored, many women access these and will normally have several such experiences in any one affected pregnancy. Access to iuMRI may become more uniformly available across the UK for specific issues like aiding diagnosis in the investigation of fetal brain anomaly cases.

[9] In a parallel way, ultrasound is also viewed more positively by parents, and less so by feminist critics such as Julie Roberts (2012a) and Jan Draper (2002) who assume the role of moral arbitrators defending women's rights.

[10] This is goes against the reasoning behind abortion rights opponents promoting ultrasound viewing in order to dissuade women from undergoing a termination of an unplanned pregnancy (Kimport et al., 2012).